DOCUMENT RESUME

ED 227 633 EC 151 089

AUTHOR Breslau, Naomi
TITLE The Impact of Childhood Disability on Black and White Families.
SPONS AGENCY Cleveland Foundation, Ohio.; Mott (C.S.) Foundation, Flint, Mich.
PUB DATE Sep 82
NOTE 14p.; Paper presented at the Annual Conference of the American Sociological Association (San Francisco, CA, September 1982). The study was also supported by a grant from the Easter Seal Research Foundation.
PUB TYPE Speeches/Conference Papers (150) -- Reports - Research/Technical (143)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Cerebral Palsy; Elementary Secondary Education; *Emotional Adjustment; *Family Relationship; Mother Attitudes; Multiple Disabilities; *Physical Disabilities; *Racial Differences; *Stress Variables

ABSTRACT

Home interviews were given to 369 families of children (3-18 years old) with cystic fibrosis, cerebral palsy, myelodysplasia, and multiple physical handicaps to determine the impact of childhood disability on families. Results were compared with those of 465 control families who had one or more non-handicapped children in that age range. A cross sectional model was used to analyze results according to four successive outcomes of child disability: family cohesion, maternal distress, family repertoire of activities, and mastery. Results suggested that child disability did not directly influence maternal distress, but did indirectly affect distress via family repertoire and mastery. Results supported the hypothesis that a disabled child in the home has a significant negative effect on family repertoire of activities, which in turn affects the mother's sense of her mastery. A lack of mastery, in turn, is associated with distress. The overall picture of the interplay among variables was somewhat different for white and black families. The effect of childhood disability on family variables and on mastery was 3.5 times greater for black than for white mothers. (CL)

**********
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
**********

Prepared for presentation at the annual meeting of the American Sociological Association, September, 1982, San Franciso, California.

ED227633

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

This document has been reproduced as received from the person or organization originating it.

Minor changes have been made to improve reproduction quality.

Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

# The Impact of Childhood Disability on Black and White Families

Naomi Breslau, Ph.D.
Department of Epidemiology and Community Health
Case Western Reserve University
School of Medicine
Cleveland. Ohio 44106
(216) 368-3716

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Naomi Breslau

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

This study was supported by grants from the Cleveland Foundation, the Charles S. Mott Foundation and the Easter Seal Research Foundation

EC151089

## Introduction

Recent U.S. statistics indicate that the proportion of children with disability due to chronic illness has increased markedly. The percentage (and number) of children with activity limitation due to chronic conditions in the non-institutionalized population has risen from 2.1% (1,418,000) in 1967 to 3.9% (2,309,000) in 1978. This rise is due in part to improvements in medical therapies which increased the survival rate and prolonged the life of children born with severe physical disabilities. The shift from institutional care to care in the home is undoubtedly reflected in these statistics as well. The burden on families may have become not only more common but also more intense, for in addition to providing domiciliary care, families are expected to obtain a widening range of professional services on behalf of disabled children as well as administer therapeutic procedures directly. Although these trends have important implications for families, the question of how families nurse and support disabled children and at what cost to their members have not yet been adequately addressed.

Previous studies have reported that severe disability in children has adverse effects on their families. The daily care of the child often depletes parents' energy and causes withdrawal from social relationships and restrictions of activities. There is evidence that marital tensions increase. although several reports suggest that in some families parents are drawn closer to one another. Two studies found that mothers of disabled children scored higher than "controls" on emotional distress and depression.

Although reports on disabled children and their families are abundant in the literature, few are based on rigorously designed studies in which control groups are used. Furthermore, previous research, as a rule, has not been based on explicit conceptual frameworks designed to explain why and how a disabled child in the home might contribute to adverse outcomes in family members.

The purpose of this paper is to offer and test hypotheses about how the conditions of life with a disabled child in the home might contribute to personal distress in mothers. If indeed families of disabled children reduce their extra-domestic activities, if home life becomes duller and more monotonous, if marital solidarity is undermined and conflict is heightened, could not then these changes themselves explain the reported maladjustment in mothers?

## Sample

Data come from a comprehensive study conducted in 1978-1979 to assess the impact of childhood disability on families and on the adjustment of the disabled children themselves. Families of children with cystic fibrosis, cerebral palsy, myelodysplasia and multiple physical handicaps were selected from four pediatric specialty clinics of two teaching hospitals in Cleveland, whose caseloads are representative of area children in these diagnostic categories. All families of patients three to eighteen years of age who resided in the Cleveland area were asked to participate in the study. From 460 eligible families, 369 (80%) complete interviews were obtained. For a comparison group ("controls") a three-stage probability sample was designed to represent all Cleveland area families with one or more children three to eighteen years old. From 530 eligible "control" families, 456 (86%) complete interviews were obtained.

In all 825 families, data were gathered from mothers in home interviews using a structured questionnaire which includes several self-administered

instruments. Trained female interviewers, matched according to respondent race, conducted the interview. A wide range of variables was covered, including the health status of several individuals in the family, sociodemographic characteristics and aspects of the social environment of the family.

## Results

It is hypothesized that a disabled child in the home exerts a negative influence on 1) family cohesion and support, and 2) the richness and variety of family stimuli. These changes impair a mother's internal resources for dealing effectively with life problems and increase the probability that she would experience distress. It is also hypothesized, and examined in further analysis, that effects vary between blacks and whites. A previous analysis of data from this study suggested that the economic impact of childhood disability was race related; specifically, that the negative effect on maternal employment, hence on maternal contributions to family income, was greater among blacks than among whites.

The proposition that family cohesion exerts an influence on the emotional well-being of mothers requires little explanation; (the social support hypothesis is familiar to all). However, the hypothesis that the variety of family activities influences the well-being of mothers might require a brief explanation. Empirical and theoretical developments in the area of social structure and personality have suggested that people's competencies for dealing with cognitively complex phenomena are formed in environmental settings. The central characteristic of a given setting is the variety and complexity of the stimuli that it offers. In this general framework, the family setting figures primarily in the development of intellectual abilities and motivations in childhood, whereas occupational settings are viewed as the arena in which

competencies continue to be shaped during adult life. However, if the substantive complexity of men's work influences their internal resources, as previous research has revealed, could not, then, the family setting affect the internal resources of mothers, especially when it constitutes their principal enviromental setting.

In this study a mother's internal resources are defined as her orientation toward self and the social environment, i.e. her sense of mastery, or the extent to which she perceives her actions as effective in mastering the environment. Mastery is viewed in this study as a factor affecting maternal distress. Implicit in this formulation is an analytical distinction between the two concepts, the first defined as a cognitive dimension, whereas the second as an affective dimension. That is to say, mastery describes a generalized belief about the social environment, whereas distress refers to negative affective experiences such as worry, anxiety and sadness. This distinction and the notion that the two variables are linked together in a causal sequence are embedded in current theories of the genesis of psychological disorder.

Maternal distress is measured by a seven-item scale developed by Pearlin and Schooler. It describes "the unpleasant feelings of which people are aware" and is specific to a woman's experience as a mother. Answers to each item range from 1 to 4 and possible scores are from 7 (low distress) to 28 (high distress). Mastery is measured by a seven-item scale developed also by Pearlin and Schooler. Answers to each item range from 1 to 4 and possible scores are from 7 (low mastery) to 28 (high mastery). Family repertoire of activities is measured by combining two scales, each with nine items, from Moos' Family Environment Scale, (FES) namely Intellectual-Cultural and Active-Recreational. Family cohesion is measured by combining two other scales from Moos FES, also with nine items each, namely Cohesion and Conflict. Internal consistency reliability of each of these

measures exceeds .80. Disability status is defined as a dichtomous variable with a value of 1 for a family with a disabled child and 0 for "controls".

Figure 1 is a diagramatic representation of the proposed model. Since stressful demands on mothers have other sources apart from having a disabled child, the model includes 5 indicators of social class and of family composition as covariates. The presence of a disabled child in the home and five covariates -- race, family income, maternal education, number of children and age of youngest child -- are taken to be "exogenous" or "predetermined variables," that is, the model says nothing about how values of these variables are themselves determined. It is supposed that two sets of family variables -- family repertoire of activities and family cohesion -- depend on the six predetermined variables as well as on other factors that are not specified in the model. It is further suggested that a mother's sense of mastery depend on the two family factors as well as on the six predetermined variables and unspecified residual factors. Finally, maternal distress is seen as a function of a mother's sense of mastery, the two sets of family factors and the six predetermined factors as well as unspecified residual factors. The model thus considers four successive outcomes of child disability.

**- FIGURE 1 -**

It should be noted that this cross sectional study has limitations with respect to the causal inferences that can be drawn from it. Some variables in the model may be reciprocally related, whereas the model focuses only on influences that flow in a single direction. For example, maternal distress may affect family cohesion, although our interest is focused only on the influence that goes from family cohesion to maternal distress. The statistical approach -- path analysis -- like statistics in general, cannot solve issues entangled with causality. These must be answered by study design. There is no ambiguity,

however, with respect to the direction of the relationship between child disability and each of the dependent variables in the model. Clearly, an association between child disability and, say, maternal distress must be interpreted as an indication that the presence of a disabled child in the home affects maternal distress. As to the relationships between family factors and mastery or maternal distress, longitudinal data may provide more definitive answers about directionality. An added methodological problem apart from directionality might be the potential bias of mothers' rating of family factors. An analysis of an existing data base on FES performed at the author's request by Moos' colleagues revealed high correlations (averiging .86) between mothers' ratings on these scales and the means of all family members, including father, children, and mothers. Such high correlations suggest that mothers' reports are valid reflections of these aspects of family life and are not overwhelmingly biased by mothers' psychological distress.

Figure 2 represents the estimates of the model using data on the 639 two-parent families in the study. In this diagram, and in subsequent diagrams, paths whose coefficients are less than .100 are omitted as empirically unimportant.

The results show that certain factors initially conceived to be causes of later outcomes are not sufficiently important empirically as direct influences. Thus, mastery and family cohesion have direct paths to maternal distress, while child disability, the key variable, as well as family repertoire of activities do not. What is revealed by the path model, that would not be revealed in a conventional regression model, however, is that factors not directly influential may nevertheless have indirect influences. Thus, child disability influences maternal distress indirectly via family repertoire and mastery. The model explains 40% of the variance in maternal distress.

These results provide general confirmation of the hypothesis: the presence

of a disabled child in the home, uninfluenced by its interrelatedness with other aspects of the environment, has a significant negative effect on family repertoire of activities, which in turn affects a mother's sense of mastery, a factor that looms large among the determinants of maternal distress.

Separate analyses were performed for black and white two-parent families. Results from these analyses are presented in Figure 3 and 4. The first result to emphasize is that the overall picture is rather different in black and white families. The causal chain which connects the presence of a disabled child in the home to maternal distress is substantially stronger for blacks than for whites. While in whites, child disability affects mothers via a single string of connecting paths, in blacks, its effect spreads in several directions and its consequences for maternal distress are amplified by multiple connections. In black families, child disability has direct negative effects on family cohesion, family repertoire of activities and mothers' sense of mastery. Among these, the effect on family cohesion is first in order of magnitude. In white families, child disability has a direct negative effect only on family repertoire. In statistical terminology, key variables in the model "interact" with race.

**- FIGURES 3,4 -**

Path coefficients are standardized so that there is meaning in the comparison between different variables in a single population. However, to compare effects between the two samples and to ascertain concretely the degree of dependence, unstandardized regressions are presented in Table 1.

The relationships among family dimensions, mastery and maternal distress are similiar in sign and size for blacks and whites, (as can be seen by inspecting the coefficients boxed in the two parts of the table). Family variables affect mastery and distress of black and white mothers in identical ways. The relationship between mastery and distress is also race constant. However, the

effect of childhood disability on family variables and on mastery is markedly different. When the various composite paths leading from Disability to Distress are totalled, the effect on black mothers is 3.5 times greater than on white mothers, (2.98 and 0.82, respectively).

This comparison indicates that childhood disability has a far greater impact on black than on white mothers. Among blacks, it weakens those family processes that constitute important social conditions that enhance the psychological well-being of all mothers, as well as erodes mothers' sense of mastery directly. In contrast, among whites a cohesive family climate and a mother's firm sense of mastery over her fate continue to shield her from experiencing distress. Neither of these important factors is weakened by child disability.

An explanation for the greater vulnerability of black families to the burden of child disability is yet to be formulated. Previous findings from this study that the effect of child disability on maternal employment (and hence on family income) is similarly race related suggests that the association might be linked in part to economic factors.

The finding that family stability in the face of one type of stressful life problem is race related has implications that go beyond the specific question addressed here. In the current behavioral science discourse on sicknenss the family is viewed primarily as therapeutic. This perspective has gone further than underscoring the relevance of the family for the health of individuals. Instead, it constitutes a bias toward viewing the family as a shelter from harsh environments and a protective mediator of stressful stimuli. The label "social support" connotes this bias. What it tactily emphasizes is the stability of the family and its autonomy.

The findings presented here, emphasizing the disparities in the capacities of families to withstand extraordinary burdens, suggest that in defining the

family as a social support we have unwisely prejudged what should be assessed empirically. It is time to devote more effort to the empirical examination of the social conditions which foster or impair the capacity of families to shield individuals from the adverse consequences of illness and other life problems.

FIGURE 1: PATH DIAGRAM REPRESENTING A MODEL OF THE IMPACT OF CHILD DISABILITY ON MATERNAL DISTRESS

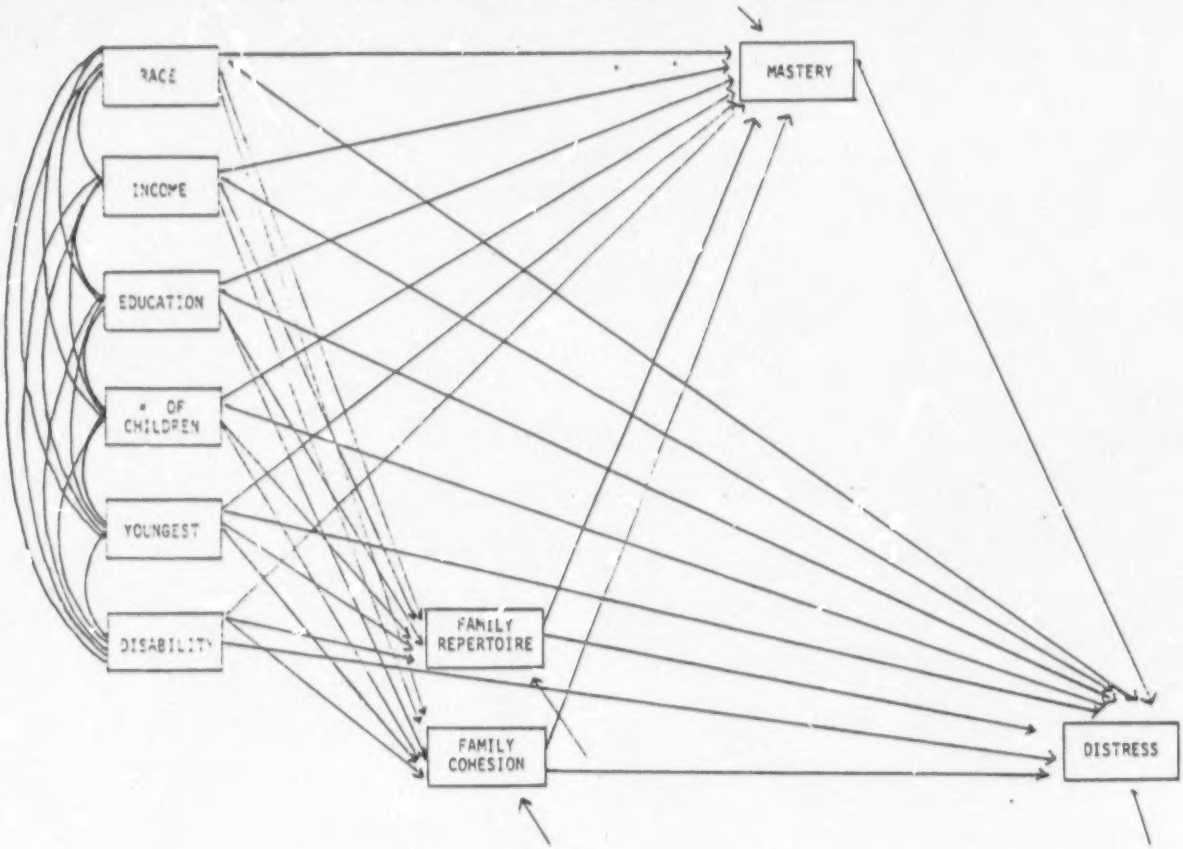


FIGURE 2: PATH DIAGRAM REPRESENTING A MODEL OF THE IMPACT OF CHILD DISABILITY ON MATERNAL DISTRESS: ESTIMATES FOR TWO-PARENT FAMILIES (N=639)

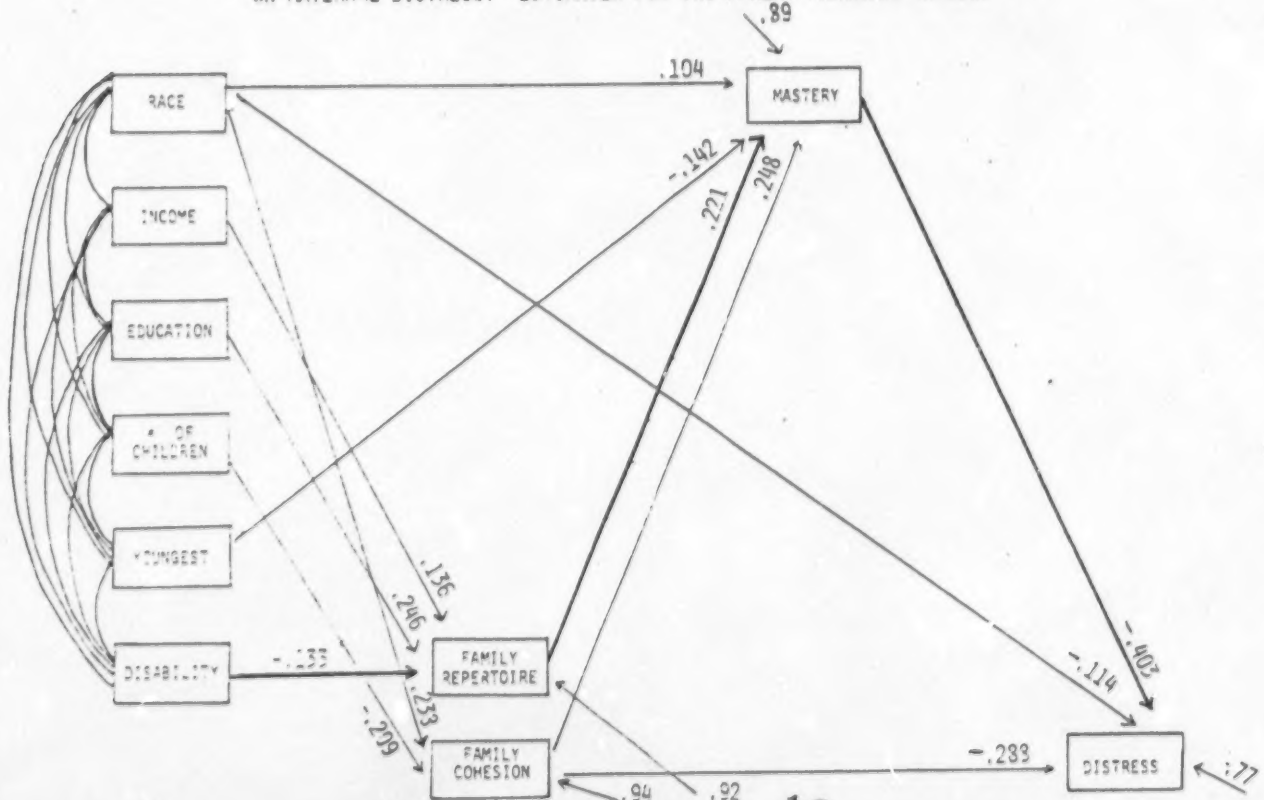

FIGURE 3: PATH DIAGRAM REPRESENTING A MODEL OF THE IMPACT OF CHILD DISABILITY ON MATERNAL DISTRESS: ESTIMATES FOR BLACKS (N=105)

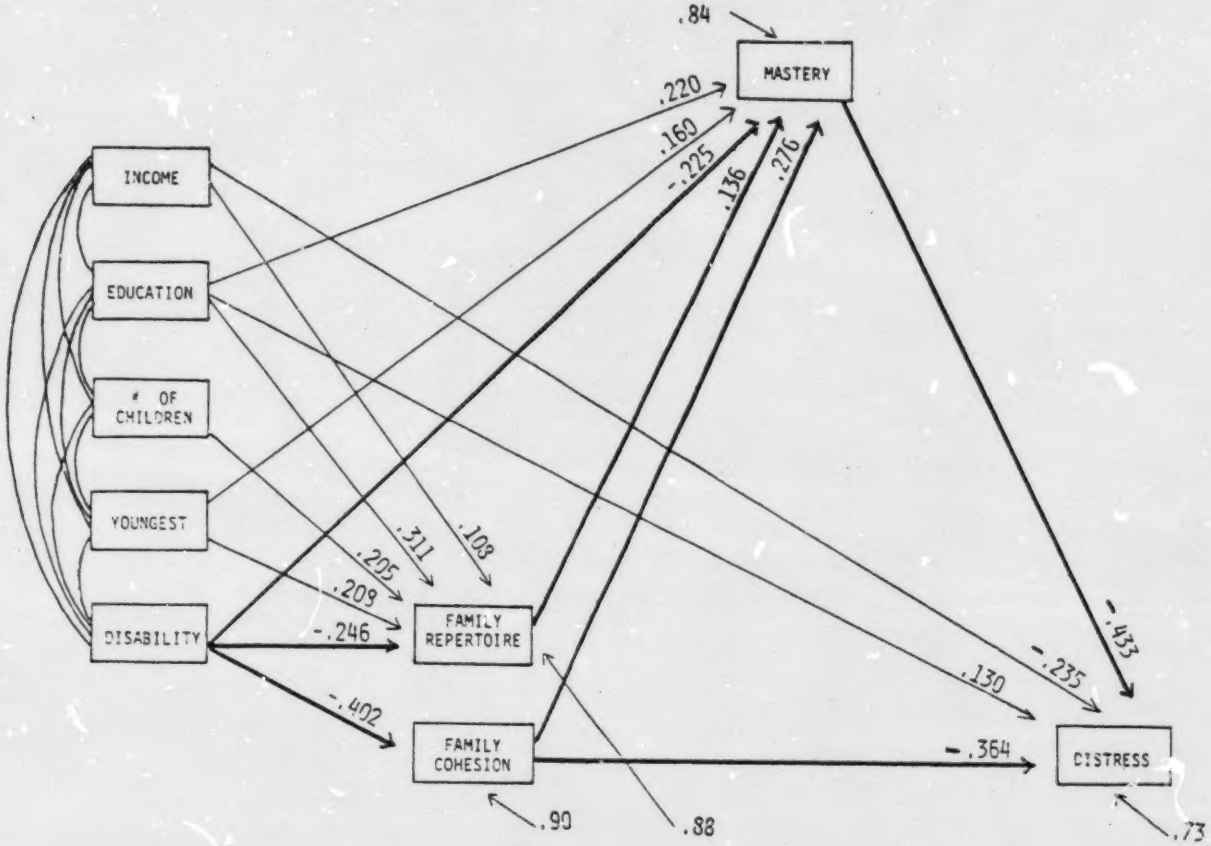


FIGURE 4: PATH DIAGRAM REPRESENTING A MODEL OF THE IMPACT OF CHILD DISABILITY ON MATERNAL DISTRESS: ESTIMATES FOR WHITES (N=534)

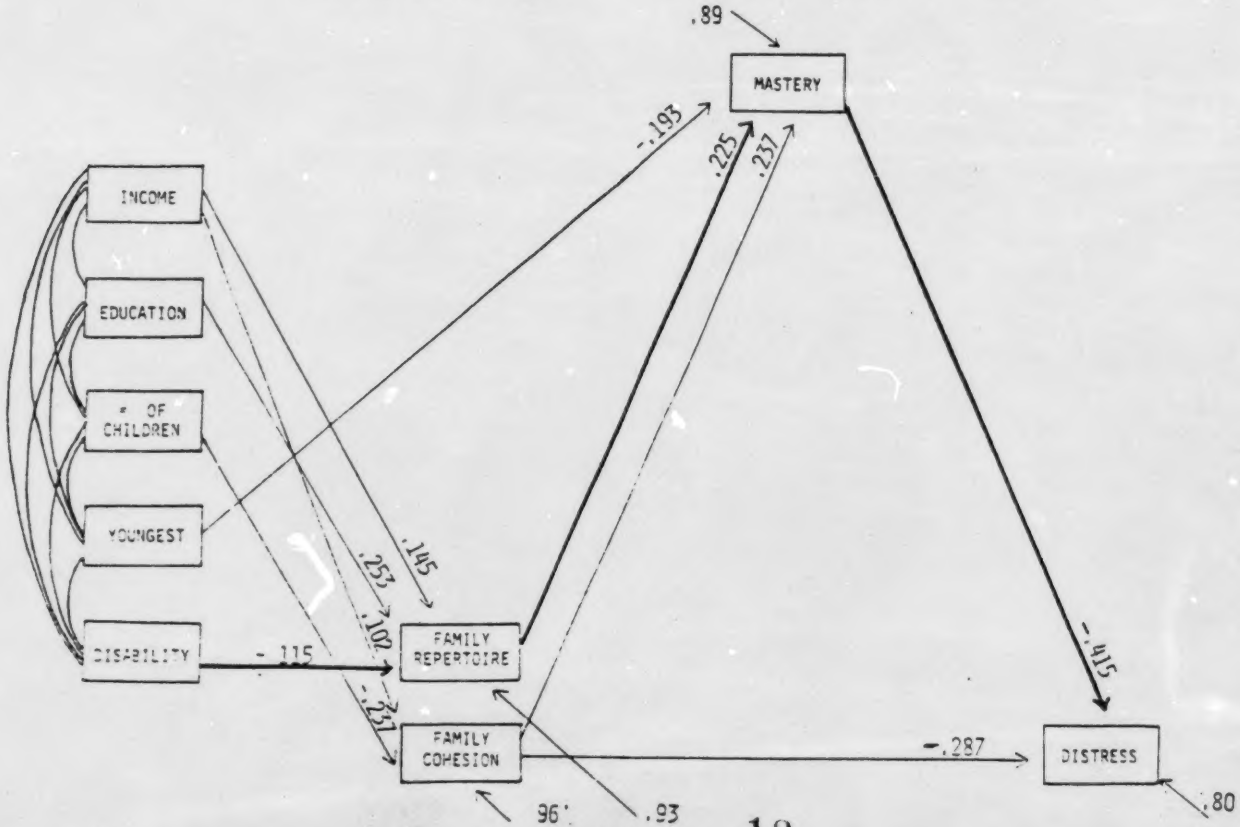

Table 1: Partial Regression Coefficients
in Successive Multiple Regressions of Maternal Distress
(two-parent families)

BLACKS (n=105)

| Independent Variable | Family Activities | Family Cohesion | Mastery | Distress |
|---|---|---|---|---|
| INCOME | .039 | -.020 | -.022 | -.110* |
| EDUCATION | .723* | -.065 | .448* | .388 |
| # of CHILDREN | .546* | -.135 | .024 | .329 |
| YOUNGEST | .150* | -.054 | .101 | .003 |
| DISABILITY | -1.885* | -2.685* | -1.508* | -.234 |
| FAMILY ACTIVITIES | — | — | .119 | .059 |
| FAMILY COHESION | — | — | .278* | -.536* |
| MASTERY | — | — | — | -.633* |
| Constant | -.296 | 9.181 | 13.422 | 10.369 |
| $R^2$ | .217 | .185 | .289 | .461 |

WHITES (n=533)

| | | | | |
|---|---|---|---|---|
| INCOME | .038* | .022* | .016 | .003 |
| EDUCATION | .406* | .017 | .074 | .031 |
| # of CHILDREN | .202 | -.566* | -.107 | -.023 |
| YOUNGEST | .017 | .029 | -.118 | -.026 |
| DISABILITY | -.836* | -.062 | -.369* | .723* |
| FAMILY ACTIVITIES | — | — | .189* | -.056 |
| FAMILY COHESION | — | — | .245* | -.422* |
| MASTERY | — | — | — | -.592* |
| Constant | 5.417 | 5.316 | 17.432 | 6.308 |
| $R^2$ | .138 | .068 | .196 | .353 |

* coefficient exceeds twice its standard error